ADULTHOOD OR OLDNESS:

IN SEARCH OF A VISION

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BY:

BRUCE C. BLANEY

HUMAN SERVICES RESEARCH INSTITUTE

2336 MASSACHUSETTS AVENUE

CAMBRIDGE, MA 02140

Introduction

In the early 1980's the field of developmental disabilities began to react to the growing old of people with developmental disabilities with a sense of discovery. Research studies, conferences and even text books announced the emergence of a new field. Conventional wisdom accounts for these activities as a response to demographic changes: The same medical advances affecting the longevity of the general population underlay the emergence of a growing population of older adults with lifelong disabilities. The appearance of an aging focus within the field of disabilities was, therefore, a predictable response to an increasingly visible "new population."

The following chapter departs from this account in suggesting that the apparent discovery of the "elderly developmentally disabled" has in reality been a process of definition, which has led to the construction of a new and devalued categorical group. As Walter Lippmann observed of a similar process, the labeling of people as "feeble-minded" in the 1920's, "We do not see and then define. We define first, then we see." The following chapter is an attempt both to critique this process of definition and to introduce a vision and conceptual framework more adaptive and responsive to adults with disabilities who are living long lives. Such a framework derives from a synthesis of "social role valorization" as conceived by Wolfensberger (1982), and an assessment of old age as a socially constructed role.

Lessons from the Field of Developmental Disabilities

Perhaps no field has enjoyed such a broad mandate in attempting to compensate the victims of social devaluation as has the field of developmental disabilities. For the past two decades that mandate has been epitomized by the principles of normalization and social role valorization,

which exhort human services to support "life conditions and social roles at least as good as the average citizen." (Wolfensberger, 1982, p. 133)

In the past decade various professionals within the field have attempted to extend that mandate, including normalization and social role valorization to older adults with developmental disabilities. In the main, this effort has suffered from a failure to recognize that oldness is itself a devalued role. Operating under the normalizing rubric of "old age-appropriate options" has, therefore, has had the perverse result of primarily replicating devalued patterns and roles.

A critical analysis and alternative to this "oldness-making" paradigm has also emerged as a parallel trend during the same period. This critique represents the first attempt to unite the theory of social role valorization with an analysis of old age as a socially constructed, devalued role (Blaney, 1989 & 1991). As discussed below, the effort to articulate a positive vision of supports to older adults may draw important lessons from this ongoing contest among visions and paradigms within the field of developmental disabilities.[1]

A Regressive Vision:
Making "People with Developmental Disabilities "Old"

At the core of the modern experience of aging is the assumption that a certain chronological age is synonymous with biological decline (Achenbaum, 1979). The "old" have been defined as a biologically bonded peer group, who have naturally congregated in their shared fate.[2] The impact of these norms is the nearly universal belief that it is acceptable for a person to lose most of his or her valued roles and to be socially segregated upon reaching a certain age.

One may assess the power and content of these stereotypes by

examining their capacity to undermine and reverse as comprehensive and widely shared a vision as that informing the field of developmental disabilities. As framed by Wolfensberger (1991), the principal theoretician of social role valorization, this core vision may be summarized as:

> The enablement, establishment, enhancement, maintenance, and/or defense of valued social roles--particularly for those at value risk--by using, as much as possible, culturally valued means. (p.21)

In this formulation, Wolfensberger substantially evolves the guiding conceptual framework of the field. The clear focus on entry into respected social roles represents a much more specific explanation and vision of the goal of human service supports than was available within the earlier principle of normalization. The goal is not attainment of the normal; the goal is support to becoming a valued member of one's community

The comparatively radical nature of this vision is clear when one realizes that most people with developmental disabilities have been excluded from valued roles, many suffering the unconditional isolation of institutionalization. In the past decade we have witnessed the actualization of this vision as even the most stigmatized among those with developmental disabilities have become workers, tenants, owners, friends, neighbors and community members. Such transformations are possible because of the emergence of formal support systems that enable and assist communities to become more hospitable to families and people with disabilities and that provide the resources and knowledge required to fully include them. Proponents of this "new paradigm" hold up the latter role in sharp contrast to the historical and still predominant role of supplanting community by a segregated continuum of service programs (Bradley & Knoll, in press).

Over the past several years, many in the field of developmental disabilities have searched for ways to support and enhance the lives of older adults with developmental disabilities by attempting to emulate the roles typically available to older adults without disabilities Now that the dust has begun to settle, it is clear that this path has not led to valued and better lives for older adults with disabilities. What has occurred instead is the construction and imposition of a powerful and new devalued role on people with developmental disabilities--the "elder DD". A look at some of the specifics of this process discloses three core patterns: retirement/role exclusion; age-segregation in virtually all service contexts; and the reformulation of institutionalization as a relevant service form.

Retirement/Role Exclusion

"Retirement programming" is an emerging means of addressing the needs of older people with disabilities (Hawkins & Eklund, 1987). "Retirement" in this context seldom refers to an actual exit from a work role because most people with mental retardation have never been employed. On the contrary, one could describe such programming as facilitating an *exit from role expectations* or in effect, eliminating individuals from any consideration for a job role. The more global presumption, introduced by this use of the term "retirement," may be described as the *withdrawal of the expectation that one will ever enter any adult roles*, such as owner, friend, spouse, community member or job holder (Matthews, 1979). The resulting role is apparent from its label, "retired client."

The program model frequently adopted by retirement programming is the *day care model*, first introduced by parent organizations in the 1950's and later rejected in favor of an educational model and more recently a vocational model. Programming comprises games, all too often very child-like, such as

plastic bowling or kick ball, some arts and crafts, group outings and the like. Often there is a group discussion format patterned after "reality orientation" -- an intervention that presumes the presence of some dementia. The model is custodial, age-segregated and resembles nothing so much as the activities programming in many nursing homes.

Such programming can clearly be characterized as "retired clienthood;" or the final rejection of the possibility of adult roles and community membership, and the definitive entry into an oldness role, where the day care model, eschewed by the field of developmental disabilities some twenty years ago, again becomes "appropriate." The reintroduction of such service patterns into the field of developmental disabilities is dramatic testimony to the power of age stereotypes, the power, in effect, to undermine the social developmental model.

Age-Segregation

The tendency to create age-segregated groups is almost irresistible. Once one has been defined as "old," the belief is tenacious that chronological age should be the major criterion for prescribing one's peer group. Indeed, this tendency derives from the very core of social policy toward people over sixty: "America's social policies for the aged are structurally segregated, particularistic policies that tend to separate the old from others in society" (Estes, 1979). Within services to people with developmental disabilities, this predisposition frequently takes the form of the development of an age-segregated subsystem of services for those identified as the "elderly developmentally disabled." Or it may be a kind of pseudo-integration, which places older adults with developmental disabilities within age-segregated

spaces for older adults without disabilities.[1] In either event, the individual remains isolated from the valued mainstream of his or her community and in separate social spaces that daily reinforce he perception that *they* are very different from the rest of *us*.

Institutionalism

A survey of residential settings for adults with developmental disabilities over the age of 60 in New York, California and Massachusetts revealed that *58% were living in public institutions*, not including nursing homes (Janicki, 1985). An even more recent study in Massachusetts found that more than half of *all* people with mental retardation, based on prevalence estimates, were either in nursing homes or state schools, a rate of institutionalization three times greater than that for younger adults (Knoll & Blaney, 1990). The pattern revealed in these studies may be described as institutionalism; this norm, that institutions are appropriate for the "old," has at best been weakly challenged and is largely condoned by professionals. Indeed, as discussed below, an unbroken historical connection exists between service patterns toward older adults and the total institution.

In this century, one may speak of at least two major deinstiutionalization movements: The first, in the period during and after World War I, replaced the scandal-ridden poor house with a system of so-called outdoor relief or welfare payments. It is important to note that, although every other category of poor-house inmate was provided an

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1 It is interesting to note the use of language in the description of these practices: Janicki, for example, uses the phrase, "integration into generic services for the elderly." Here, 'integration' refers to services that are thoroughly *segregated* by age, while 'generic' describes the *categorical* services of the aging network, not to the intended meaning — services utilized by all valued members of the community. Matthew Janicki, Address to Conference on Aging and Developmental Disabilities, University of Maryland, September 16, 1986.

alternative, older adults were left to languish in these institutions. The "old" were not deinstitutionalized because, alone among the classes of the poor, they were viewed as having no rehabilitative potential (Harber, 1985). Beginning in the 1920's, the functions of the poor house devolved to the state mental hospital, which by the mid-1930's, predominantly housed people over sixty who lacked both income and family support.

In the second major deinstitutionalization, beginning in the late 1960's, both mental institutions and institutions for people with developmental disabilities were decried as anti-habilitative. For older adults, however, the institution continued to be viewed as an appropriate setting: As the surveys above illustrate, they *remained* in the state school. Many older adults were also "transinstitutionalized" to nursing homes, and the size of the nursing home population more than doubled during the high tide of deinstiutionalization in the late 1960's and early 1970's.

During the 1980's there were attempts to give institutions for people with developmental disabilities a new lease on life as *high technology hospitals and hospices* for the old.[2] This trend reflects a kind of organizational preservation instinct at work. Proponents of institutionalization for people with developmental disabilities, a field in which institutionalism has perhaps been more thoroughly challenged then in any other, are focusing on the one area of ideology and social policy where the institution is alive and well — services to older adults. Indeed the norm that is engulfing adults with developmental disabilities who have lived long is

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2 Currently, three state schools in Massachusetts have substituted "geriatric units" or "cottages" as the only principle of specialization and grouping for "residents" who are above their mid-fifties. Wrentham State School in Massachusetts has become a national center for the reformulation of thes state institution as a valid service form for the "old" with mental retardation. This process of "geriatrizing" the state institution is visible throughout the country, especially in the mid-West, England and the mid-Atlantic states.

increasingly "they need institutions."

Post-adult: The Master Role

The field of developmental disabilities brings out in bold relief the primary social patterns generated by age-based stereotypes. Perhaps because the field has only recently been confronting issues of aging, or because people with developmental disabilities had never before been defined as "old," the events of the past ten years constitute a kind of natural laboratory in which one may see the impact of a relatively pure culture of age-based stereotypes and patterns on a field whose governing ideology sees stereotypes as anathema. What do these core patterns of retirement, segregation and institutionalization reveal about the contemporary "oldness" paradigm?

At the heart of the oldness paradigm is the construction of a role new to the twentieth century, *post-adulthood.*

> The process that began in the 1930's when
> retirement and a retirement age were instituted on
> a broad scale has finally culminated in the
> institutionalization of a post-adult period in the life
> cycle in which persons past retirement age are
> officially considered incapable of dealing effectively
> with their own lives.... The old, simply because of
> their age, are deemed incapable. In essence they
> are assumed to be "post-adults" (Matthews, 1979, p.
> 132).

Evidence for this insight can be seen in the impact of age-based

stereotyping upon people with developmental disabilities. What has been most life-defining for people labeled "developmentally disabled" has been their exclusion from adulthood both ideologically and socially. People labeled developmentally disabled were not only physically separated from our communities by brick walls, as might happen to someone who breaks the law, but defined as "outside" of and incapable of becoming adults. People with real or alleged intellectual impairments were defined as *pre-adults*, people who were, above all, distinguished by never possessing the abilities to enter and perform adult roles (Blaney, 1985). As people were freed from institutions, they were not at the same time freed from this child/pre-adult role. They were still expected to be "outside" the adult world of jobs, relationships such as marriage, adult intimacy or friendship and incapable of active community membership. A whole separate world was structured for these pre-adults-- sheltered day programs, separate homes and separate spaces for recreation--in which they would be cared for by adult staff.

The recent preoccupation with the aging of people with developmental disabilities may at first strike one as contradictory. Much of the past decade has been consumed with convincing the field and the public that people with developmental disabilities leave childhood, grow up and become adults. Why then the rush to define people with developmental disabilities as "old" when they cross over some magical chronological divide? What links the pre-adult status of people with developmental disabilities to their susceptibility to being labeled and engulfed by "oldness" expectations?

The movement from "developmentally disabled" to "old" turns out to be not much of a transformation at all. At the root of both stereotypes is the expectation that such people are incapable of performing adult roles. The ease with which people labeled "developmentally disabled" come to be labeled

"old," therefore, occurs at the intersection of pre-adulthood and post-adulthood. What indeed is happening is that people who have never been able to enter adulthood are entering a new role that likewise precludes adult roles and relationships. In effect, people with developmental disabilities are going from pre-adulthood to post-adulthood without passing through adulthood.

The core service patterns of retirement/role exclusion, segregation and institutionalization, embraced and promoted within the field of developmental disabilities, are rooted in the presumption that the typical older person is incapable of occupying adult roles or of coping with the social spaces frequented by adults: Post-adults must be with their own kind where they can be more efficiently cared for while they engage in a variety of non-productive and generally trivialist routines. The imposition of "retired clienthood" upon adults with developmental disabilities assures their ongoing dependency upon human services and professionals. Their clienthood is, indeed, doubly affirmed. The process described above reveals the depth and extent of dependency-making, the core dynamic of the "oldness" paradigm.

A Creative Vision: Adulthood

Behind these patterns is a unique predicament, obvious in the field of developmental disabilities, but no less influential, in fact, probably more so, within the field of aging: What is the role of human services in a situation in which the replication of social norms is in its essence also a process of devaluation and age segregation?

Social role valorization as a theory of policy and service design has always distinguished the culturally *valued* from the typical or normative. The implicit corollary, bearing directly on the problem described above, is:

When social norms are themselves devaluing,

human service actors must reject the *typical* and

seek instead to support *valued* processes and

outcomes.

The field of aging, especially within the past five years, has embarked

on a major paradigm shift toward a values base more congruent with social

role valorization, as articulated here by Robert Binstock (1983) in his Kent

Memorial Lecture to the American Gerontological Society:

Ultimately one would need to have public policy

framed within a *non-ageist political context* in

which the *heterogeneity* of older persons in

recognized. I can see no reason why our

organization cannot refocus to be more self-

consciously concerned with *age-relations* rather

than the aged (p. 139, emphasis added).

Binstock, Neugarten, Estes and other influential policy analysts are

urging the field of aging to abandon its notions of the "old" as a homogeneous

group to be congregated and, instead, to view citizens over the age of sixty as

the most internally diverse and heterogeneous of any age group (Neugarten,

1982). At the same time, the field, as in Binstock above, is stressing that

aging policy should be focused on support to intergenerational relationships

rather than on age-segregation.

The application of the principle of social role valorization to older adults

has made it apparent that the oldness role is simply not valued and that

duplicating that role and its accompanying service patterns leads to

devaluing outcomes. The vision we are recommending, (replacing the present

core of post-adulthood) is the widely shared and deeply internalized picture of

those in their seventh decade and beyond as first and foremost *adults*. Just

as "people-first" language has assisted our society to experience the essential commonalties among people with and without disabilities, adopting "adult-first" language regarding people who are now victims of "old-first" labeling, will support a comparable social experience of intergenerational commonalty and continuity.

Holding human services and indeed our broader society accountable to the standard of valued adult roles for older adults represents a crucial addition to the critique offered by Binstock and others. Without specifying such a goal, mere refinements of post-adult roles are likely to persist as valid goals. The recent invitation by the fast food industry to our "senior citizens" to enter dead-end service jobs is a relevant example of one such pernicious refinement of post-adulthood.

After more than two decades of application as a critical tool to debunk pre-adult roles, social role valorization now challenges us to make a qualitative break with post-adult roles and service patterns. The value base and configuration of the current service system will not be touched by superficial reforms; it must be fundamentally transformed with a focus on the key constituent parts: role exclusion, segregation and the embrace of custodial/institutional models.

Operationalizing a Vision of Adulthood

From Role Exclusion to Role Continuity and Entry
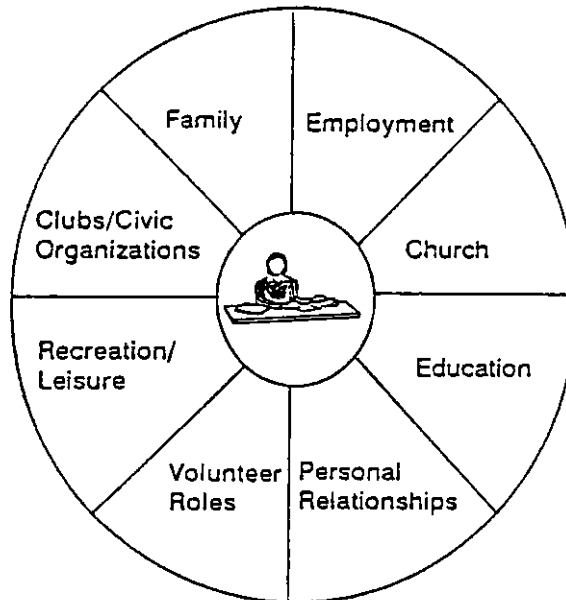
The chart above represents possible life areas which describe adult involvements and interests. With this as a backdrop, there are several questions we must answer regarding any support systems we design in order to move from a system that generates devalued roles to a system that supports valued social roles.

- Within each life area, what post-adult roles and relationships does this person experience?

- Within each life area, what adult roles and relationships does this person experience? Is he or she at risk of losing any of these roles. How can he or she be supported in maintaining these roles and relationships?

- How often does he or she participate in these roles and relationships?

- How would you describe these roles and relationships in terms of their quality: How much of a contributing role to a community association?

How much of a decision-making role within his or her family?

• What are the current roles of human services in promoting or preventing
this person's maintenance or entry into adult roles and relationships?

• What other roles should formal or informal supports play in promoting
adult roles and relationships?

It will be useful to answer these questions for yourself and then for
someone you know who is defined as "old." Closing the gap between the two
sets of responses offers a graphic illustration of what should become the
driving mission of supports to adults who have lived long lives.

From Segregation to Personal Community Relationship and Membership

Binstock's call for "age-relationship" or intergenerational integration,
occurs within the context of a system of supports that exemplifies age-
segregation. The presumption that older adults are essentially different from
the rest of us and similar to each other has led to the extensive
"seniorization" of social space within the past twenty-five years. One finds
senior centers erected adjacent to community centers and virtually every
human activity has now been age-segregated including sports and college
classes.

Retirement
Community

Nursing Home

Senior
Center

Elder
Housing
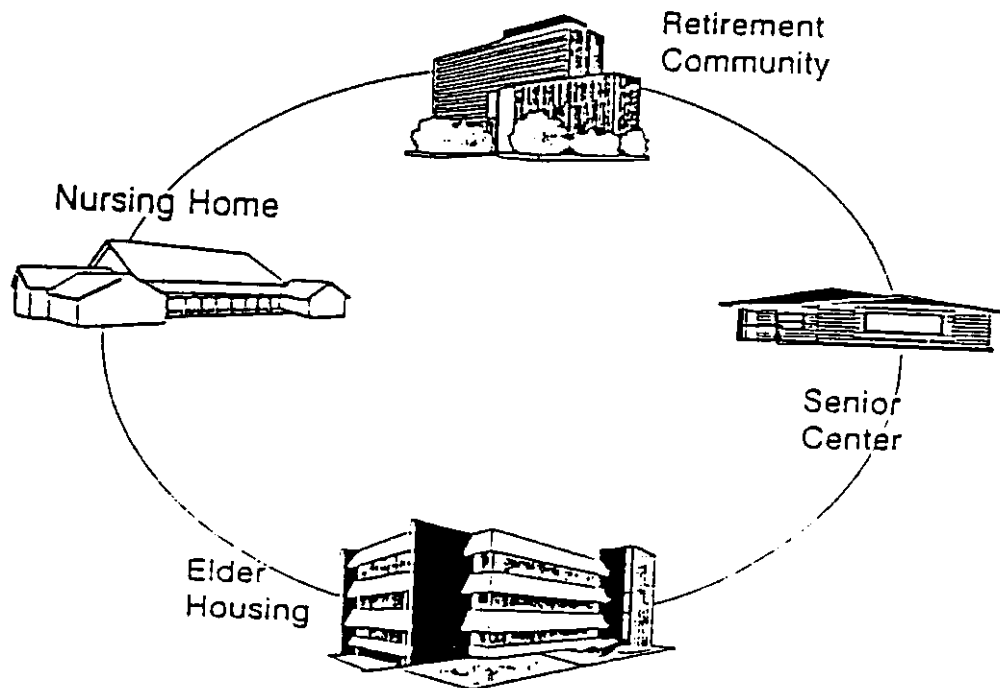
The challenge for the aging system is to make a commitment to social integration that includes at its center a plan to *desegregate* its own system. In what will surely be an agonizingly difficult process of redirection, social role valorization offers the aging system a penetrating analysis of social integration, including guidelines for accomplishing such broad-based desegregation.

The key insight offered by social role valorization and missing in the vision of the aging network is the distinction between *physical* and *social* integration. Currently the aging network has made a commitment to physical integration — to the physical presence of older adults in our communities. Through the home care system, senior housing, adult day care and other supports, aging services are attempting to prevent the physical removal of older adults to institutions.

Each one of these service forms is, however, mainly socially segregated, erecting substantial barriers to the social participation and relationship of older adults within the *mainstream community*. In effect, the aging system uses socially segregated service forms to accomplish physical presence. One of the key insights of social role valorization has been to redefine physical integration, not as a goal but as a precondition, a *means* to the far more significant outcome of social integration, to personal membership, participation and relationship with one's community.

What would a commitment to social integration look like for the aging system? The alternative is not difficult to envision. It is the inclusion of older adults within the social spaces and organizations utilized by valued members of one's own community, such as housing, community centers, clubs, and valued paid and voluntary job roles. At the heart of the matter must also be a visible demonstration by the aging system that it is

desegregating — ceasing to promote senior centers, senior housing and age
segregated supports such as adult day care. At the same time the aging
network must allocate resources to intergenerational housing and social
opportunities which bring the generations together as adults contributing to
their shared communities.

Judy Heumann (1986) of the World Institute on Disability has cogently
articulated this issue:

> The same type of segregated service delivery
> system has been created for the elderly that
> younger disabled people and their supporters have
> been fighting for years to disassemble. I do not
> want to see myself or other disabled people who
> have fought so hard for integration being relegated
> back into segregated programs whey they grow old.
> (pp. 9-10)

The challenge for the field of developmental disabilities is to look to its
own paradigm for guidance and inspiration rather than to the "oldness"
paradigm. Reduced to its essentials, the latter paradigm is the very same
bio-eugenics ideology which was decisively rejected by the major reformers
within the field of developmental disabilities, such as Dybwad, Wolfensberger
and Blatt, when they launched the field as we know it: They discarded the
notion that mental retardation was the result of some reified biological
essence that necessitated the social removal of people with mental
retardation. The field must now affirm its paradigm by similarly rejecting
the biomedicalization and segregation of adults with developmental
disabilities who are living long lives.

Unlike the field of aging, the field of developmental disabilities

possesses in its recent history a powerful knowledge base with which to combat this new incarnation of eugenic thinking. Within the past three decades, it has accomplished a profound paradigm shift. All that holds back a similar effort regarding adults who have lived long lives, with and without disabilities is perhaps best captured in the reflections of Henri Nouwen (1982):

> As long as the old remain strangers, caring can
> hardly be meaningful. The old stranger must first
> become part of our inner self and a welcome friend.
> (p. 89)

In the worst case, the field of developmental disabilities will add a new *them* to the historical roll call of devalued identities, wasting many lives in the process. In the best case, we will see and conceptualize *adults like us who are living long lives* and will marshall our hard-won, new paradigm on behalf of all of us who are growing old.

From Institution to Community

As we pointed out above, there is an unbroken historical connection between people defined as "old" and institutionalization. Quite simply, there has never been a deinstitutionalization of nursing homes. In a very real sense, the continuing presence of the institution as a relevant service form in the vision of the aging network may be the major obstacle to creating an alternative vision of older people as adults like us. Whether characterized as "houses of death" or as the social space for the delivery of "unloving care," nursing homes are periodically revealed as anti-habilitative on a scandalous level. Yet they remain on the service continuum of the aging system with no initiative forthcoming within the aging network for deinstitutionalization.[3]

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3 The Nursing Home Reform Act of the Omnibus Reconciliation Act of 1987 (OBRA-87) has

The continuing validation of the total institution for older adults is evidence of the extent to which the aging network has embraced the image of post-adulthood for older adults. Only people whom we consistently viewed as virtually post-human would be consigned to social spaces that no one of us would even imagine inhabiting.

Social role valorization has grown out of a twenty-year effort to create an institution-free society. People with cognitive impairments at least as severe as late-stage Alzheimer's disease and with physical impairments comparable to any encountered in nursing homes have left institutions and are living among us in their homes and apartments. This twenty-year experience provides the knowledge and skills to accomplish a similar communitization of older people from nursing homes.

Knowledge is, however, not the central issue. Our society knows how to support people outside of institutions. The issue is how our society, including its human services, has chosen to define older people. Post-adults live in institutions. Adults live in next apartment.

Conclusion

The vision presented above is simple and hopefully, compelling: It is a picture of a society in which people who have lived into their seventh decade and beyond are experienced as adults exactly like the rest of us, individuals sharing the common spaces, relationships, opportunities and roles available to all valued adults. It is a vision of the role of the human service system as a key support to an interdependent community in which the gifts and desires of the individual are affirmed and the stereotypical thinking behind

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occurred as an initiative of the developmental disabilities network. In its interpretation by the states and the Health Care Financing Administration, OBRA seems to constitute as much a validation of nursing homes as an appropriate service form as it does a very modest first step toward deinstitutionalization.

categorization and segregation is set aside. Finally, it is a vision of a culture in which not only have age stereotypes been transcended but in which "old" has become *irrelevant* as a descriptor or predictor of who we are.

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